



# Down but not out

The unique challenges faced by adolescents with a chronic illness or injury and how schools can best support them. By Darragh O'Keeffe.

**B**rendan\* was just about to start high school when he became ill. Before the onset of his illness he was academically capable and socially competent.

His condition meant prolonged absences from school and before long his grades were slipping. Increasingly school took up a much less important space in his life.

Eventually Brendan caught up academically, but the social disconnection caused by the combination of a change of school and his health condition remained.

When he returned to school he felt he was being treated differently. He was often subjected to teasing and bullying.

"They would yell out names. One did a drawing with half a brain on it and someone wrote 'jump in the lake' on it," he said.

Making friendships has been very difficult. When describing the students he spends time with at school he said they are associates, rather than friends.

"That is my goal for this year, I have set myself the aim of establishing a friendship group, because I miss not having friends," he says.

Brendan is not alone.

In fact, 12 per cent of Australian adolescents live with a chronic health condition – a number experts say has risen dramatically in recent years.

As a result, most teachers will have a chronically ill student in their class at some point in their career.

Since 2007 a Victorian research project, 'Keeping connected' has been investigating how ongoing illness or physical injury can affect students' experiences of social life, education and their emerging sense of identity.

Researchers at the Melbourne Graduate School of Education, at the University of Melbourne, have been working with 31 young people, aged between 10 and 18, whose schooling has been interrupted by illness and have spent significant periods of time at the Royal Children's Hospital, Melbourne.

"We wanted to get a better understanding of how their situations change and the impact of that, the ups and downs. It's their perspective. At the heart of the study is the voices of the adolescents themselves," says researcher Julianne Moss.

"We have a team of eight researchers from different backgrounds in health and education, as a major goal is investigating how the child sits at that interface."

The study participants include 21 females and 10

## In this story

- 12 per cent of Australian adolescents live with a chronic health condition
- Researchers are investigating how ongoing illness affects a young person's experiences of social life, education and emerging sense of identity
- They have found schools play both a connecting and isolating role
- The responses by schools and teachers to these students can be varied.

males, with varying conditions – either acquired or from birth. They come from city and country areas across Victoria and Tasmania.

The project began by giving each of the adolescents a camera to "portray their lives visually".

"It provided the starting point for the conversations and gave us an insight into their personalities and their lives," says Peter Ferguson, another researcher on the study.

"It was effective in giving them something they could talk about comfortably with the researcher. Often it was family, friends or pets. Over time the relationships between researcher and adolescent developed.

"We conducted the interviews at their home, on their territory. We would talk about what had been happening in their lives, how they felt about those changes; their day to day struggle," he says.

During the course of the conversations the young people were clear that their health problems did not define who they were. They actively tried to make the most of their often difficult situations and were determined to have interesting, rewarding and meaningful lives.

"The interviews captured the journey these young people are on. Sometimes they were enjoying life, and other times they were sombre; the light and shade," says Moss.

"A major focus was on identity, how they saw themselves and how their health condition fitted into that. Most saw their condition as something they put up with, rather than being a defining feature. As one girl said, 'I am not my illness,'" adds Ferguson.

The study highlighted the important role school plays in these young people's lives, particularly as a stabilising influence.

Schools can play both a connecting and an isolating role for the adolescents. The routine and social aspect can be beneficial, even if attendance is interrupted by their health condition. However,

school may also unwittingly reinforce a student's sense of difference, with misplaced kindness potentially causing more harm than good. There is also the threat of bullying and isolation for "different" students, the researchers say.

One positive school initiative highlighted in the study included a science teacher who dedicated a class to one young person's health condition while she was in hospital so her classmates could better understand it. Another school ran a personal development camp that discussed diversity and acceptance of others, while another organised a study group in a student's home to help him stay connected academically and socially.

There were also a number of well-intentioned actions that weren't welcomed by the adolescent. These included a student who felt uncomfortable with a teacher aide who was seated in the classroom but not introduced to the young person so as not to highlight they needed assistance. In another example, a group of students was brought to visit the adolescent in hospital, which the student wasn't expecting or comfortable with.

"The way the young people felt about school and how they were treated varied. For some it was very positive, for others it was just another problem they had to deal with," says Ferguson.

"Sometimes the school simply handled it badly. Other times, the school didn't know what to do. And in other occasions the adolescent themselves didn't know how they wanted the situation handled.

"There's a real unresolvable issue for the young people around how they want schools to respond. On the one hand they want support, but on the other they want their privacy. They often weren't sure how to go about obtaining both," he says.

"It's hugely important that schools remember the child remains a learner, even while they're patients," says Dr Julie Green, head of research at the Royal Children's Hospital Education Institute, the industry partner in the project.

"They don't leave that at the hospital door. Whatever we can do to help them keep the connection to their identity as a learner is important," she says.

Building a bridge that traverses the hospital-home-school divide is also essential. There must be ongoing communication across the three spectrums, Green says.

Often when the young person returns to school, after a medical crisis or a lengthy hospital stay, they are left out of the loop, Moss says.

"I don't think schools realise quite how much young people can manage their situations, be it in terms of their health or education. Often when they return to school they are left out of the conversation, things are done for them and to them. The school fails to involve the young person," she says.

Similarly, the response of individual teachers, in terms of helpfulness and support, varied greatly.

"We found, largely, that if a teacher was very helpful and supportive it was because they chose to be, they had a particular interest. It wasn't because of a structural element within the school," says Moss.

"Teachers need to take a flexible, child-centered approach. So learning plans can be tailored around whatever circumstance arises, when it arises," says Green.

"Another tool is to develop e-portfolios so the child's work done in the hospital travels back to the school. It's a more seamless bridge across the two.

"It's also important for schools to have a key contact person in regard to the child. That person relays information and is the mediator between the different settings. We have liaison roles, for example, who provide information to the school and the education region the child comes from. It provides an important link."

Interestingly, despite the often prolonged and repeated absences from school, the adolescents never disconnected with education.

"They still said they wanted to go on and study, do training to become a teacher or nurse and so on. Whenever they discussed future plans it always

### About the project

Keeping connected is a three year, longitudinal study. It is led by a multidisciplinary team which includes researchers from the Melbourne Graduate School of Education, University of Melbourne, LaTrobe University, Deakin University and the Royal Children's Hospital Centre for Adolescent Health. The project is funded by an Australian Research Council linkage grant and the Royal Children's Hospital Education Institute as industry partner.

invariably involved education," says Ferguson.

In fact, the study has broadened to include retrospective interviews with adults, aged up to 25 years old, who experienced chronic health conditions as adolescents. These interviews echo the sentiment that education remains a key importance for young people affected by illness.

"Despite long periods of absence from school, all these young adults had found some way into education, be it through TAFE or university," says Moss.

"Another interesting thing we're seeing is the future career choices the adolescents are making," adds Ferguson.

"They are obviously greatly affected by what they have experienced, as many said they wanted to work in caring professions, such as health and education. One boy who said he wanted to become a vet and work at the zoo acknowledged it was because he wants to look after animals.

"Similarly, when we asked the young people

why they had volunteered to be part of the study, the common answer was that they didn't want anything from it themselves, they just hoped it would help other students with similar problems," he says.

That desire to help and work with others was clear on the hospital ward too, says Green.

"Often the young person builds relationships with other patients. In the adolescent ward we have discreet learning spaces which provide an opportunity for young people to experience the social aspect of learning. We also link young people from the adolescent ward with younger children at the outpatient clinics in a buddy system, giving them a chance to learn from each other.

"Social networking is very important for maintaining that link. Kids learn from each other, so we have a suite of IT, laptops at the bedside and learning space to facilitate that connection."

The researchers say the study has evolved and will now also include detailed case studies of the adolescents, interviews with their parents, the retrospective interviews mentioned above and focus groups with health and education professionals.

They aim to have the study's final findings ready by the end of this year.

\*Name has been changed.

Go to [education.unimelb.edu.au/keepingconnected](http://education.unimelb.edu.au/keepingconnected). For information on how to support a young person with a health condition, go to [rch.org.au/education](http://rch.org.au/education).



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